What’s Missing from NAMI and Pro-Psychiatry: A Lack of Lived Experience

By

Maria Mangicaro -

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Recently, I had the opportunity to share my experiences as a former psychiatric patient with author Gary Null, PhD, for his upcoming documentary about psychiatry. During our conversation, I brought up the concerning fact that many leaders of the pro-psychiatry movement successfully launched by the National Alliance on Mental Illness (NAMI) and other organizations have never been mental healthcare consumers themselves. I believe that advocates who have not experienced psychiatric treatment lack the ability to fully comprehend the suffering many consumers endure from adverse drug reactions.

This is, I think, a moral imperative. The use of all pharmaceutical products really is a “buyer-beware” situation—and since many psych patients become forced consumers, their advocates have a duty to be educated and concerned with adverse reactions.

During my time as a psychiatric consumer, I both experienced and witnessed much wrongdoing within the system. Among the most grievous was the liberal prescribing of psychiatric medications without consideration or warning of their known risks. Back in the late 1990s, under forced treatment for psychotic episodes labeled bipolar disorder, I had no choice but to accept drugs that I knew were causing me harm—including Parkinson-like symptoms and tardive dyskinesia that rendered me unable to care for myself. I soon realized that in order to find drug-free solutions for my health conditions, I needed to educate myself.

Once I learned more about possible medical issues that can underlie “mental illness” and alternative therapies to address them, I was able to get the correct diagnosis behind my symptoms: toxic encephalopathy from workplace chemicals. Only after I incorporated evidence-based treatments and various complementary therapies into my regimen did I begin to recover. I also developed skills to successfully advocate for myself and became passionate about promoting positive system change on behalf of others. (I shared the details of my story in a blog for Mad in America last year.)

As an advocate for family members, I have seen how easy it is for prescribers to overlook their patients' harmful, drug-induced side effects. These adverse reactions were either ignored or diagnosed as symptoms of a separate illness and treated with additional drugs. That is what happened to my late brother Lenny, whose nightmare of misdiagnosis and overdrugging, then proper care and temporary recovery I also shared here. I recognized the suffering he was enduring when his doctors continued to promote the drugs he was on as safe and effective. If not for my and my family's persistence in advocating for him, the prescribers would not have acknowledged his drug-induced conditions.

Questioning the "facts" of the pro-psychiatry mindset

Mind you, like the rest of the pro-psychiatry movement, I used to be one who put all of my trust and faith into medical professionals and the "medicine" they prescribe to treat perceived psychiatric disorders. My initial exposure to it came in the fall of 1999, when I attended my first NAMI conference in Syracuse, New York. With Pulitzer Prize-winner William Styron giving the keynote address, the event attracted over 500 NAMI members and many mental health professionals who served as guest speakers. I was very excited to connect with members of NAMI and I wanted to learn everything I could about what seemed like a very strong and influential not-for-profit advocacy organization.

After I listened to the conference presenters, observed the audience's responses, read NAMI-created materials, and spoke with NAMI members, it became obvious that they conceptualized "mental illness" in a very limited way. Much like programming a robot, NAMI presented us with pro-psychiatry "facts" that seemed designed to be memorized and repeated. While based on a foundation of family-to-family support, the organization seemed to be leading the cause of keeping all mental health consumers on psychiatric drugs at all times and at all costs because they believe the drugs are life-saving…and that there are no other effective treatment options. They seemed to form their beliefs based on anecdotal evidence that medications work for some, and therefore should work for everyone—all the while turning a blind eye to the harmful side effects their loved ones experienced.

My experience at the NAMI conference led me to the conclusion that the group was an ally of the pharmaceutical industry. A later U.S. Senate investigation confirmed my suspicion, revealing that in two years alone (2006-2008), the pharmaceutical industry had contributed over $23 million to NAMI. After a newspaper expose, NAMI's then-leader even acknowledged that the group received some 75% of its funding from drug companies.

This same movement, which has helped bio-psychiatry to flourish, fuels a dangerous agenda in strong support of forced, possibly lifelong treatment. This agenda deprives consumers of best-practice standards that emphasize individualized care and consider the underlying causes of psychiatric disorders.

A loved one’s medication-induced nightmare

Based on my extensive research during and after my family’s experience with psychiatry, I believe that individualized, holistic treatment provides the most realistic opportunity for mental health consumers to live a healthy life. The recent struggles of another family member whose medication-induced symptoms were misdiagnosed as a psychiatric disorder has only reinforced this belief— and convinced me of the importance of becoming educated on the many adverse reactions prescription drugs can cause.

Let’s start with the fact that the warning labels on pharmaceutical products should be taken very seriously. Like many other psychiatric consumers, I learned the hard way that adverse reactions really can happen and when they do, prescribers don’t know how to help. A loved one I’ll call Max is currently on disability due to an adverse drug reaction that can best be described as medication-induced torture. Last fall, shortly after being prescribed a fluoroquinolone antibiotic for a cold, they suffered acute toxic neuropathy. Peripheral neuropathy, a very painful condition that affects the nerves outside the brain and spinal cord, is a known adverse reaction to that type of antibiotic. In addition, neuropathy was listed as a possible adverse reaction on several other medications they were being prescribed, which included two types of blood pressure medications, a gout medication, three different nasal sprays, and an over-the-counter allergy medication. As confirmed by a pharmacist, polypharmacy greatly increased the chances Max would suffer this “side effect.”

While it was obvious to me that the cocktail of drugs Max was prescribed quickly induced a very severe and possibly life-threatening condition, it took a lot of advocating on my part to convince medical providers this was the case. From the onset of their symptoms, I started keeping a journal, photographing their adverse reactions, and filling a binder with all of their medical records. I’m so glad I did, because one night, after starting a new medication to treat what one specialist considered to be restless leg syndrome, they woke up screaming in pain. It started with a sudden sharp pain in their right shoulder; within a few hours they could not raise their right arm, had edema (swelling) in their right hand, and the right side of their face had a noticeable droop.

Based on my past experience and research, I was convinced they were in a crisis situation and experiencing additional toxic reactions. We went to the ER for help, but

they simply diagnosed Max with unrelated pain from arthritis and were planning to discharge them. At the very least, I thought, the doctors should give them an IV to help flush out the toxins, but the hospital would not provide that treatment for someone who they believed was dealing with arthritis.

Before they let Max go, I literally begged an emergency room doctor to have the hospital pharmacist evaluate the medications Max had taken over the past month. The doctor agreed to having just the current medications evaluated and soon returned to tell us that he was surprised to learn that one of the blood pressure medications Max was on could cause permanent peripheral neuropathy! He agreed to administer an IV, and it did help relieve some of the distress my family member was experiencing. This was the fifth time Max had been to the emergency room seeking help for medication-induced toxic reactions that continued to be misdiagnosed. It took a hospital pharmacist to confirm what I was suggesting all along.

After a total of nine trips to the emergency room, enough was enough. In addition to the anticonvulsant medication prescribed to treat neuropathy, the only help doctors had to offer Max were psychiatric drugs for problems like insomnia and anxiety, which were being caused by the unbearable pain of toxic neuropathy. Rather than using more drugs to treat an obvious drug-induced condition, Max decided to go on disability to focus on getting off the offending drugs and healing their underlying health conditions. First, they tapered off of all of the medications with the known side effect of neuropathy, including the one for gout. By using the advice from Dr. David Perlmutter’s book Drop Acid and other alternative strategies, they were able to do so safely. For over a month now, their uric acid level and blood pressure have remained within normal ranges and they have not been back to the emergency room. We also researched supplements and treatments to help with their neuropathy symptoms. One such treatment has been BEMER therapy, which is helping my family member find some relief for a disabling condition that continues to flare up very easily.

And since I filed a formal complaint with the hospital, the mainstream doctors are now working to help Max in ways that may actually be useful. For example, it placed them in a coordinated care program where their caregivers can collaborate on the best treatment, and we have open access to hospital resources that will provide answers to all our questions. Max’s neurologist also provided a referral to specialists at the University of South Florida because, he admitted, this was the first time in his 30-year career that he had ever diagnosed a patient with medication-induced toxic neuropathy and was unfamiliar with appropriate treatments.

Going forward, Max continues to have muscle weakness, flare ups of neuropathy, chronic fatigue, and hypersensitivities to chemical exposure/food allergies. The lessons we’ve learned from this scary and frustrating episode are not new. First, that self-advocacy works: Mental health care consumers and their families need to speak up, making sure that providers have ruled out all possible underlying medical

conditions before they make a psychiatric diagnosis and prescribe dangerous medications. Second, know your medication side effects! They can mimic the symptoms of other illnesses and/or be life-threatening. Read the package inserts on all prescriptions fully, and raise any concerns with doctors and pharmacists.